**GRASSROOT, HOME-BASED REHABILITATION SERVICES FOR CHILDREN WITH NEUROLOGICAL DISORDERS IN UGANDA:**

**A PILOT STUDY**

Part I: Report

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Part II: Appendices are digitally available upon request.

**Abbreviations**

ADL Activities of Daily Life

CBR Community-Based Rehabilitation

COPM Canadian Occupational Performance Measure

CP Cerebral Palsy

IGA Income Generating Activities

FW Fieldworker

OURS Organised Useful Rehabilitation Service

PO Partner Organisation

SDG Sustainable Development Goals

STEP Support Tools Enabling Parents

UNAC Ugandan Association for people with Cerebral Palsy

**Abstract**

*Background:* In an earlier study on the Liliane Foundation’s support to children with disabilities and their caregivers, a significant positive effect on their lives has been reported. However, the study also identifies opportunities for improvement in the quality of care, such as connecting children, caregivers, and other stakeholders to exchange experiences and knowledge, as well as providing more knowledge and skills for mediators such as local partners and fieldworkers. Thus, the STEP programme, which stands for Support Tools Enabling Parents, was implemented for fieldworkers from four African countries. STEP is an intervention package aiming at training, supportive coaching of fieldworkers combined with a number of tools such as a logbook, WhatsApp groups and a Smartphone App.

*Methods:* An evaluation study was carried out on the effect of STEP on the lives of children with a neurological disorder (mostly Cerebral Palsy), their caregivers and fieldworkers, in Uganda. Eleven case studies were selected, with data collected for each of these children, their respective caregivers, and fieldworkers before the launch of the pilot, during, and at the end one year later. Quantitative and qualitative evaluation methods were used: the COPM, a caregiver survey, and questionnaires for caregivers and fieldworkers. In addition, logbooks providing assessment, goal setting and monitoring information of the disabled child were reviewed as well as field notes from coaches and researchers. Preliminary outcomes were discussed in focus groups with fieldworkers and caregivers. The study design is an evaluation study with pre- and post-tests using a pre-experimental design

*Results:* This study found an improvement in daily life skills of the children as well as an increase in knowledge, confidence, and skills of caregivers and fieldworkers. The STEP approach is therefore seen as a good start in providing home-based services provided that these, along with hospital-based services, are connected to each other. Next referrals to specialists, parent support groups, and income generating programmes are made when needed.

*Conclusion:*

The study is a pilot study to find out whether STEP could have a positive effect on the children, caregivers and fieldworkers involved. Further research with a more controlled design in other local organisations has to be carried out to establish the results of this pilot study.



**Foreword**

“My name is Christine; I am living with Cerebral Palsy (CP). I got this disability at the age of 9, after suffering from cerebral malaria. Today I’m writing to you on behalf of children living with CP and on behalf of caregivers. They are my brothers and sisters who are severely affected by CP, who cannot even tell you what they are feeling

Caregivers and children with CP are isolated, they are looked as outcasts. Many of them cannot earn a living because they have been denied the opportunity to do so. There are many other needs that the child has. In current projects, not all those needs are met. We come up with proposals to address the needs that we think are the problems in the community.

How wonderful it is STEP was created, that has come up with a holistic method of going to the community. For many years, programmes have been there to address the issues of persons with disabilities. But there is no programme that has ever been designed to listen to the families. They have not been given a chance to share what they are going through.

What can we do? Most of you are CBR workers or work with CBR workers. I would like to say that with STEP we are breaking the barriers of institutionalisation. Come on, rehabilitate me within my community. Rehabilitate that child within his or her family. Don’t isolate them. And that is STEP. That is trying to see that the child really is being loved, is being rehabilitated within her family. That STEP can kill two birds with one stone. It looks at the child with the disability but also at the caregiver.

There is a need for awareness. And how are we doing it? Are we ready to put off our titles and go to the communities, put ourselves to the level of the communities? Because without this they will not open to us.

Thank you so much.

Christine Kirungi

Ugandan Association for people with Cerebral Palsy (UNAC)

1. **The STEP programme**
   1. **Introduction**

In low-income countries (LICs), the prevalence of cerebral palsy (CP), which in Luganda is called ‘okusanyalala kwo kubwongo’, seems slightly higher than in high-income countries (HICs). A study in Uganda (Kakooza-Mwesige et al., 2015) shows a prevalence of 2.9 per 1,000 children out of a sample of 31,756 children between the age of two and 17 years versus roughly 2.0 – 2.5 per 1,000 children in high income countries. The prevalence numbers in Uganda did not include the children with cerebral palsy who have passed away. It is estimated that the mortality rate of children with severe cerebral palsy is higher in LICs than in HICs. The causes of cerebral palsy also differed with preterm birth as a major risk in HICs and postnatal causes such as cerebral malaria and other infections for LICs, which is about 25% versus 10% in HICs. The preterm birth mortality in Uganda was higher compared to HICs (Kakooza-Mwesige et al., 2015; Dan & Paneth, 2017).

The Liliane Foundation aims to increase social participation and equality opportunities for children with disabilities. The core strategy is Child Empowerment: “increasing the child’s personal, social, educational and economic strengths. The strategy consists of two elements: the development of children (Child Development) and the accessibility of their environment (Enabling Environment)” (Liliane Foundation, 2019).

Holle et al. (2013) show in an impact study in Uganda on the support of the Liliane Foundation on the lives of children with disabilities and their caregivers that this support makes a significant difference on their lives. The study also showed room for improvement in quality of care, such as connecting children, caregivers and other stakeholders, exchanging experiences and knowledge but most of all provide more knowledge and skills for mediators, which include local partners and fieldworkers.

The International Classification of Functioning, Disability and Health (ICF), developed by the WHO and used within rehabilitation services across the world, is a framework used in the STEP project. It fits a community-based rehabilitation (CBR) approach as it focusses on what a person can or cannot do and achieve, not only by looking at body functions but also at the interaction between body functions and body structures, activities, participation, personal and environmental factors (WHO, 2002; see Figure 1). Services should not only take place at an individual level, but also on family and community level (Schneider & Hartley, 2006).

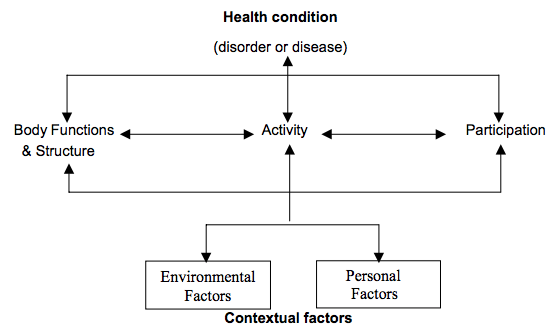


Figure 1. The ICF, a framework to represent factors that influence disability (WHO, 2002)

In 2018, Liliane Foundation initiated a one-year pilot project called STEP: Support Tools Enabling Parents, to address the needs for desired capacity in the provision of (re)habilitation services, in the Lake Victoria Region (Uganda, Kenya, Tanzania) and Cameroon. The actual study report concerns a pilot study and focusses on one country: Uganda. The project focuses on training fieldworkers, in particular competences to improve care and basic rehabilitation services for children with a neurological disorder and their families. Fieldworkers, overall, are people with limited professional background and opportunity for training, who are closest to the families (Rule, 2013). They are the ones who are visiting, or can visit, the communities and homes of the families regularly. Fieldworkers often lack the necessary expertise, with the lack of or inappropriate assistive devices further aggravating the problem. As such, the STEP project aims to train fieldworkers in helping caregivers in providing better quality and thus more effective interventions for children with neurological disorders, specifically.

STEP is a training package consisting of: training loops, i.e. three training weeks over a period of 1 year with face-to-face coaching in between, and tools such as: a WhatsApp group for intervision, a log-book which basically is a a client record that helps the fieldworker to systematically recording assessment, setting goals, designing strategies and monitoring progress of the disabled child, the RehApp-CP, a Smartphone App that can be used as a vital resource and the Connect online platform where all training materials and resources can be found.

As Thelen and Smith (1994) point out, the goal of development should be to seek out information allowing for a “functional match between what the environment affords and what the actor can and wants to do” (p. xxi as cited in Vermeer & Magyarszeky, 2014, p. 48). Thereby, in developing a training programme that aims to improve the capacities of both fieldworkers and caregivers in the rehabilitation of children, the needs but also the wishes, hopes and dreams of both children with neurological disorders and caregivers have to be taken into consideration. Furthermore, these wishes must be contextualised within the living circumstances of the child, to ensure the relevance of STEP to ensure that ultimately the interventions will lead to an improved quality of care and thus quality of life of each child and family.

**1.2 Aim and research questions**

Overall, this evaluation study aims to establish the outcomes of the STEP pilot on the lives of children with neurological disorders, caregivers and fieldworkers. This leads to the following research question: *What are the outcomes of the STEP pilot on the lives of these children, their caregivers and fieldworkers involved with the family?* This research questions can be answered with the following sub questions:

1. To what extent did the skills on activity and participation level of the child increase?
2. To what extent did the knowledge, attitude and skills of the caregiver about their child’s situation change?
3. To what extent did the knowledge, attitude and skills of the fieldworker change?

**1.3 Design**

This study is an evaluation study with pre- and post-test using a pre-experimental design. The methods are case studies with both qualitative and quantitative measuring instruments. The study led to a selection of 11 cases for which we have complete data sets for both the children and caregivers as well as from the fieldworkers to evaluate progress achieved by the STEP pilot.

**1.4 Training**

The STEP training package consists of three learning loops spread over one-year alternating training weeks with face-to-face and mobile coaching (see Appendix B for an overview of the overall training schedules and topics). The content of the first training has been established by a training needs-assessment that was conducted prior to the first training and before the baseline data collection. The training needs-assessment was done in focus group discussions with children with neurological disorders, children without a disability, caregivers of children with neurological disorders, caregivers of children without a disability, and fieldworkers. These participants were different from the ones in this pilot evaluation study (see Appendix A for an overview of the questions and collected answers).

Based on this information, the training content was developed and also used for the development of the RehApp-CP (see Appendix A for the outcomes of the needs-assessment).

During the pilot period, care and services were provided for 40 families in Uganda by a team consisting of speech therapists, occupational therapists, physiotherapists, and a physiatrist. Additionally, the RehApp-CP was used which included the content of the training in a compressed and visual way with illustrations throughout supporting the information given. Care and services were supported by the use of a logbook which was kept by the families and used by both the caregiver and fieldworker (see Appendix C). The logbook was explained in the training. The logbook follows a rehabilitation cycle that reflects the main steps of the rehabilitation process: interview🡪observation🡪writing a plan🡪action.

**1.5 Sample**

The study focusses on children with neurological disorders and their caregiver(s) and their fieldworkers. Each of the partner organisations (POs) in Uganda (n=4), randomly identified 10 children with neurological disorders, 40 children in total, based on the following criteria:

* Living within a close proximity to the centre where the fieldworker is located.
* Having a central neurological disorder: cerebral palsy, meningitis from Tuberculosis and Malaria, viral and bacterial meningitis, sickle cell anaemia, HIV-related or microcephaly.
* The child lives with a caregiver and not in an institution.
* Children between age 1 to 8 years, as a typically developing child is expected to reach maximum scores within mobility, self-care and social function domain at the age of 7 to 8 years (Smits et al., 2019).

It was not clear with most families who had set the diagnosis. Two families hadn’t heard of CP yet, neither in English nor in Luganda, and it was unclear whether they had CP or not. It is more likely that they have a developmental delay and/or an intellectual disability.

The total sample of 40 children received services provided by the STEP pilot programme over a period of one year. Of those, 11 cases with complete data sets were initially selected (see Table 1). Of the 11 cases, one had moved to an unknown location and hence was excluded from the sample. Each family was supported by a fieldworker. A total of three fieldworkers were involved in these case studies. In seven of these case studies, besides the mother, the father was still living at home and involved in taking care of the child. None of the children had visited a kindergarten, nursery school nor primary school so far, as their caregivers wanted them to be at home so that they could play with other children and stay close to them. The age is reflected in years as the caregivers could often not remember the exact date of birth (See Table 1, 2, 3).

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Child demographics** | | | | | | | | | |
| *Child* | *Gender* | *Age* | *Health condition* | *Cause* | *Type* | *GMFCS* | *MACS* | *CFCS* | *EDACS* |
| A | male | 4 | CP | Jaundice post-natal | Dyskinetic | 5 | 5 | 5 | 4 |
| B | female | 4 | CP + suspected Spina Bifida | N/K Mother fell at 8 months pregnancy | Spastic, unilateral | 1 | 2 | 3 | 1 |
| C | female | 4 | Developmental Delay | “Slow learner” |  | 3 | 3 | 5 | 1 |
| D | male | 5 | CP | During birth: too long in birth canal | Spastic, bilateral | 3 | 2 | 2 | 2 |
| E | female | 2 | CP | During birth: too long in birth canal | Not sure yet | 5 | 5 | 5 | 4 |
| F | male | 6 | CP + obstetric brachial plexus palsy | Pneumonia post-natal | Dyskinetic | 5 | 5 | 4 | 4 |
| G | male | 6 | CP?  (DD/ID/ASD) | Meningitis post-natal |  | 3 | 1 | 5 | 1 |
| H | male | 5 | CP  (looks like microcephaly) | During birth: too long in birth canal (uterus not open, child oxygen problem) | Spastic, bilateral | 5 | 5 | 4 | 3 |
| I | female | 3 | CP | Jaundice post-natal | Dyskinetic | 3 | 3 | 3 | 3 |
| J | male | 8 | CP | Malaria mother pre-natal | Dyskinetic, spastic | 4 | 3 | 3 | 2 |

*Table 1. Selected cases, demographics of the child. Age given is at end line evaluation.*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Caregiver demographics** | | | |
| *Child* | *Gender* | *Age* | *Relationship status* | *Home owner* |
| A | female | 21-25 | Married | Rent |
| B | female | 40-60 | Grandmother, widow | Own |
| C | female | 30-40 | Married | Rent |
| D | female | 40-60 | Grandmother | Own |
| E | female | 30-40 | Married | Own |
| F | female | 30-40 | Single mother | Rent |
| G | female | 30-40 | Married | Rent |
| H | female | 26-30 | Married | Rent |
| I | female | 30-40 | Married | Own |
| J | female | 30-40 | Married | Own |

*Table 2. Selected cases, demographics of the caregivers*

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Fieldworker demographics** | | |
| *Name* | *Gender* | *Age* | *Educational background* |
| 1 | female | 24 | Bachelor’s degree in arts education; trained as secondary level teacher |
| 2 | female | 24 | Bachelor’s degree in social work and community development in disability |
| 3 | female | 22 | Until senior 4 |

*Table 3. Selected cases, demographics of the fieldworkers, they worked at three different organisations.*

**1.6 Measuring instruments**

The study used two instruments prior to the pilot period: (1) a survey which was adapted from a study by the London School of Hygiene and Tropical Medicine (Zuurmond et al., 2018) and (2) the Canadian Occupational Performance Measure (COPM) (Law et al., 2014). The fieldworkers filled in questionnaires at three moments during the training weeks of the pilot and they used a logbook for each family. We used an interview guide to support interviews with the fieldworkers (see Appendix D). To increase internal validity, these measuring instruments were selected to connect the training content, the expected outcomes and the measuring instruments are as follows:

* A survey provided information about the demographics of the children and caregivers and external factors such as living conditions and socio-economic conditions.
* The COPM captures a client’s self-perception of performance in everyday living, over time.  The COPM is an individualized, client-centred outcome measure.
* A questionnaire provided demographic information of the fieldworkers as well as perceived scores of knowledge and skills level and statements on disability.
* A logbook, based on the ICF, gave the families a voice in telling their story, the difficulties their child and themselves face, shared decision making on goal setting and actions, and monitoring of progress in skills of the child.
* An interview guide for the fieldworkers, together with the COPM and survey used at the start and end of the pilot with the caregivers, gave information on how changes were similarly or differently perceived between caregivers and fieldworkers.
* Focus group discussions were used to identify similarities and differences in the participants.

**1.6.1 Survey**

The survey of this study was adapted, with consent, from a study in Ghana focusing on the impact of a support programme for caregivers that have a child with cerebral palsy (Zuurmond et al., 2018). The survey includes demographic information of children and caregivers such as age, gender, family situation, living conditions and social-economic conditions. The survey further provides information on disability knowledge, rehabilitation services, education and perceived quality of life using Cantril’s ladder, which also is used in a longitudinal study by Young Lives to ask about subjective well-being and satisfaction in life (Cantril, 2016, Yorke & Ogando Portela, 2018). Young Lives refers to this measurement as the Ladder of Life question. At the end of the STEP project, the survey was adapted and used in a semi-structured interview to go more in-depth into the answers given. Questions that remained, focused on: level of knowledge and confidence of the caregiver, satisfaction about the fieldworker, interaction with the fieldworker, frequency of home visits, usefulness of and involvement in interventions, Ladder of Life, changes over the past year and main reasons for this change (See Appendix E).

**1.6.2 COPM**

The COPM focusses on daily life performance problems. This means the difficulties a person faces in a normal day, how important they are to him or her, which of those are a priority to deal with at this moment, how these activities are going right now and how satisfied the person is at this moment in time with that activity. It uses semi-structured interviewing with open ended questions combined with scores for importance, performance and satisfaction. The interviewer used the COPM scoring card showing the scores on a line of 1 to 10. At the end of the project, the COPM was re-scored to see to what extent skills of the child had changed (Law et al., 2014).

**1.6.3 Questionnaires**

Three questionnaires were filled in by fieldworkers directly before and after the first training and at the end of the second training. These questionnaires were based on demographic information of fieldworkers such as age, gender, and educational background. Furthermore, questions included competences such as knowledge on training topics and overall evaluation of the training (see Appendix F for the third post training questionnaire. The other questionnaires can be shared upon request).

**1.6.4 Logbooks**

The fieldworkers used one logbook per family to guide the received support during the training period. The logbook was kept by the families and included information from observations and interviews of the fieldworkers with the caregivers, based on the ICF framework (WHO, 2002), a rehabilitation plan, monitoring logbook and evaluation of the rehab plan (see Appendix C). The logbook shows how the fieldworkers applied their knowledge and skills and to what extent skills of the child increased. The difference between the COPM and logbook is that the COPM was done by the researchers and the logbook filled out by the fieldworkers on basis of their assessment and discussions with the caregivers.

**1.7 Organisation of the study**

**1.7.1 Setting**

This study took place in one of the target countries: Uganda, via one strategic partner organization, Katalemwa Cheshire Home for Rehabilitation Services, and involved four of their partner organisations.

**1.7.2 Data collection**

Data collection at baseline was done by a Ugandan occupational therapist with experience in paediatric rehabilitation, who was also the co-coordinator for the STEP project. He was trained in the use of the measuring instruments prior to the start of the programme. The endline evaluation was done by the same person together with a rehabilitation specialist from the Liliane Foundation, involved in writing the STEP training modules and coaching of the fieldworkers. The interviews with the caregivers took place in their homes, with the fieldworkers at the Katalemwa Cheshire Home in Kampala and at their personal workplace. All interviews were transcribed and observations of the living conditions and interactions of the child and caregiver were written down.

At various moments in time, data was collected, starting prior to the first training. Figure 3 shows an overview of the timeline of the STEP pilot and the data collection moments.

*Figure 3. Timeline STEP pilot.*

**1.7.3 Data analysis.**

A qualitative approach was used to analyse the different types of data and to connect information provided by the caregivers and the fieldworkers into 10 case studies. We choose for a descriptive report of this evaluation study to design further actions, such as upscaling by the current partner organisations, to other partner organisations and to other countries. Similarities and differences were discussed with the caregivers and fieldworkers in separate focus group discussions at the rehabilitation centre.

**1.7.4 Ethical aspects.**

All participants gave written informed consent after explanation of the study prior to the interview, both in English and in Luganda. The consent forms were also translated into Luganda. The outcomes of this study will be shared with the participants after publication. All names in the data were anonymized and replaced with letters. The director of Katalemwa Cheshire Home gave formal approval for doing this evaluation study (see Appendix G).



1. **Results**

The outcomes of the STEP project will be described per child/selected case study, and per fieldworker. The names of children are replaced by letters and the names of fieldworkers by a number, and specific names of POs by ‘rehabilitation centre’.

**2.1 Perceived effects of the training: per child**

Table 4 summarizes the outcomes of this evaluation study per child (A till J) on the used measuring instruments.

*1. COPM performance*

Perceived performances on a 10-point scale increased in 9 of the 10 cases from low (Child A) to relatively high (Child F).

*2*. *COPM satisfaction*

Satisfaction of the caregivers with the current performance of activities, measured on a 10-point scale, increased to a high extent in 3 cases (Child E, F and I), to a moderate extent in 5 cases (Child A, C, D,G and H) and decreased in 2 cases (Child B and J).

*3. Current level of knowledge*

The level of knowledge at the post-test measured on a 5-point scale scored relatively high in 4 cases (Child D, F, G and I), moderate in 5 cases (Child B, C, E, H and J) and low in 1 case (Child A).

*4. Current level of confidence*

The level of confidence to cope with the difficulties of the child scored on a 5-point scale was relatively high in 6 cases (Child A ,B, C, E, I and J), moderate in 3 cases (Child F, G, H) and low in 1 case (Child D).

*5. Current satisfaction with the fieldworker*

Satisfaction with the fieldworkers, scored on a 5-point scale, was high in 5 cases (Child A, D, G, H, I and J), relatively high in 2 cases (Child E and F [with a difference between mother and father]) and moderate in 2 cases (Child B and C).

*6. Current satisfaction with the fieldworker interaction*

Satisfaction of the caregivers about the interaction with the fieldworker, scored on a 5-point sale, proved to be high in 5 cases (Child A, D, E, G and J) and relatively high in 5 cases (Child B, C, F, H and I).

*7a. Current frequency of the visit of the fieldworker*

The frequency of the visit of the fieldworker range from 1 time a month (5 Children), via 2 times (4 Children) to 3 times a month (1 Child).

*7b. Preferred frequency visit*

Seven (7) caregivers wanted to have more visits of the fieldworker (range from 1 till 8 times a month). For 3 caregivers the frequency could remain.

*8. Better help needed form the fieldworker*

Seven (7) caregivers answered Yes, and 3 NO.

*9. Usefulness of the information provided by the fieldworker*

All caregivers are positive about this information.

*10. Do the parents feel to be involved in the provided care*

All caregivers are positive about the way they are involved in the care for their children.

*11. Current position of the caregiver on the Ladder of Life (=satisfaction with quality of life)*

At the post-test and scored on a 9-point scale (from WORST to BEST) 5 caregivers (Child A, B, E, I and J) feel that they are relatively satisfied with the quality of their live, 3 caregivers are moderate satisfied (Child D, F, and H), and 2 caregivers are relatively low satisfied (Child C and G [with a difference between mother and father]).

*12. Current feeling of the quality of life of the child perceived by the caregivers*

During the post-test 2 caregivers feel relatively content with the quality of life of their children (Child B and J [with a difference between mother and child]), 4 caregivers have moderate feelings (Child A, G [different for mother and father], H and I), and 4 have relatively low feelings (Child C,D, E and F) about the quality of life of their children.

*13. Current feeling of the quality of life perceived by the fieldworkers themselves*

One fieldworker (of Child A – F) feels relatively positive with his quality of life. One fieldworker (of Child G and H) says that over time his feelings improved from low to a bit better. And another fieldworker (of Child I and J) says that her feelings changed from low to good.

*14. Current feeling of the quality of life of the child perceived by the caregivers*

One fieldworker judged the quality of life of 4 children (Child B, C, D, and E) quite high and of two children (Child A and F) as moderate. One fieldworker perceives the quality of life of two children (Child G and H) as changing form low to moderate, and another fieldworker perceives the quality of life of 2 children moderate (Child I and J) as changing from low to moderate.

*15. Current perception by the fieldworker of the quality of life of the caregiver*

One fieldworker (of Child A – F) did not answer this question. The field worker of 2 children (Child G and H) perceives the quality of life of the caregiver of these children as changing form low to rather moderate and another fieldworker perceives the quality of life of 2 other children (Child I and J) as changing from moderate to quite good.

Table 4. Summary of outcomes evaluation study. 1. COPM performance difference, 2. COPM satisfaction difference, 3. Level of knowledge current (0-4: no, low, some, good, lots), 4. Confidence level current (0-4: no, low, some, good, lots), 5. Fieldworker satisfaction current (1-5), 6. Fieldworker interaction current (1-5), 7. Frequency visit fieldworker current (a), preferred (b), 8. Better help needed from fieldworker or not, 9. Information or exercises fieldworker useful, 10. Do you feel involved, 11. Ladder of Life caregiver current (1-9), 12. Ladder of Life child current (1-10), 13. Ladder of Life fieldworker (1-10), 14. Ladder of Life child (1-10), 15. Ladder of Life caregiver

\*+ PSG 2x/m

Child G: scores for 11 and 12 were given by respectively mother and father, hence double scoring

Child J: scores for 12 were given respectively by mother and child, hence double scoring

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| 5 |  |  |  |  |  |  | 2>4 | 2>4 | 5>7 | 5>7 |
| 14 | 6 | 7 | 8 | 7 | 8 | 6 | 2>4 | 2>4 | 4>6 | 4>6 |
| 13 | 7 | 7 | 7 | 7 | 7 | 7 | 1>5 | 1>5 | 2>8 | 2>8 |
| 12 | 4 | 7 | 2 | 3 | 3 | 3 | 4/1 | 6 | 5 | 7/8 |
| 11 | 6 | 6 | 3 | 4 | 6 | 4 | 3/1 | 5 | 7 | 6 |
| 10 | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| 9 | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| 8 | N | Y | Y | Y | Y | Y | N | Y | N | Y |
| 7b | = | = | > 3-4/m | = | > 2x/m | > 3x/m | > 4x/m | > 8x/m | > 3-4/m | > 1x/m |
| 7a | 2x/m \* | 1x/m \* | 2x/m \* | 2x/m \* | 1x/m \* | 1x/m \* | 3x/m | 1x/m | 2x/m | 1x/2m |
| 6 | 5 | 4 | 4 | 5 | 5 | 4/2 | 5 | 4 | 4 | 5 |
| 5 | 5 | 3 | 3 | 5 | 4 | 4 | 5 | 5 | 5 | 5 |
| 4 | 4 | 4 | 4 | 2 | 4 | 3 | 3 | 3 | 4 | 4 |
| 3 | 1 | 3 | 3 | 4 | 3 | 4 | 4 | 3 | 4 | 3 |
| 2 | 1 | -0,8 | 0.3 | 2.2 | 5.75 | 7 | 1.8 | 3.2 | 5.5 | -1.25 |
| 1 | 1.4 | 0 | 2.4 | 2.2 | 5 | 6.5 | 2.6 | 3.2 | 5 | 2 |
| Child | A | B | C | D | E | F | G | H | I | J |

**2.2 Additions from focus group discussion**

Preliminary outcomes of the interviews with the caregivers were discussed in a focus group with 7 out of the 10 caregivers. The research questions provided the guideline for the discussions.

In general, the outcomes of the measurements and the interviews were confirmed during the focus group discussion.

Most caregivers mention having learned from the fieldworker how to communicate with their child and that they were trained to handle their child for example during feeding, positioning and play.

All caregivers want their child to go to school but find it difficult to find an appropriate school.

Regarding the frequency of the home visits, some caregivers say the fieldworker doesn’t come as often as in the beginning and seems to be less committed. Another mother states that it’s also the caregivers’ own responsibility to call the fieldworker.

**2.3 Perceived outcomes of the training per fieldworker**

The fieldworkers were interviewed at their workplace, at their employers’ centre or own shop. The interviews were transcribed, and the fieldworkers checked their transcription and added or corrected where needed. Table 5 summarizes the perceived outcomes of the STEP training for the three fieldworkers (FW’s) involved in this study.

**outcomes FW 1 FW 2 FW 3**

- learned that caregivers differ in need for contact +

- gaining more practical rehabilitative skills + + +

- more confident in expressing + +

- learn what to do with materials around +

- better communication with colleagues and other professionals +

- better understanding of causes of disability + +

- better understanding of causes of change in the child + +

- idem in the caregiver +

- better understanding of possibilities of other therapies +

- learn to work in a home situation + +

- learn to see the advantages to cooperate with other professionals +

- experienced the usefulness of the logbook + +

- changes in attitude towards disability +

- could better explain usefulness of rehabilitative actions +

- learned to set up appropriate goals +

- learned to use simple language +

- learned the use of assistive devices +

- learned the advantages of the CP App +

- learn to improve knowledge in parents +

- creating more awareness in the caregivers +

- training caregivers in carrying out daily activities +

- helping caregivers to find a school for their child +

- providing information to teachers +

- learned to adapt own skills to the extent of the disability of a child +

- learned to involve able bodied children in their actions +

- learned how to improve her actions +

- learned the usefulness of home visits +

*Table 5: Summary of the perceived outcomes of the STEP training for the three fieldworkers (FW’s) involved in the study*

***2.4 Additions from focus group discussion***

Preliminary outcomes of the interviews with fieldworkers were discussed with all three fieldworkers in a focus group discussion. During this focus group discussion posters with quotes from caregivers and fieldworkers about their children as well as caregiver and fieldworker expressions were discussed.

* Reviewing the quotes, the fieldworkers state that “we now understand more things”. They also express a wish to receive feedback right after a home visit instead of getting at a later stage a whole list of advice and/or corrections.
* The fieldworkers did not like the logbook at the introduction, but now love it after understanding the purpose and benefits much better.
* They learned that children with disability can “do more for society and are more useful when you take care of them” and that “empowered disabled people expose their community in a positive way”
* They want to read more about ideas that could help them to better offer support for severely disabled children.
* They do feel that caregivers sometimes expect more of them than they can offer, e.g. paying of school fees. Overall, the fieldworkers feel appreciated and sometimes caregivers wants to give them gifts.
* The fieldworkers say that there are still gaps in their knowledge: “there are things you still need to learn”.



1. **Discussion**

**3.1 Evaluation of the project**

Overall, the STEP project was perceived by caregivers as a way to support caregivers in how to better take care of their child. Some caregivers thought STEP was the parent support group and some heard it helps to provide services at home to support caregivers and children.

**3.1.1 Research questions**

*Overall research question: What are the outcomes of the STEP pilot on the lives of these children, their caregivers and fieldworkers involved in the family?*

Mayne (2001) suggests an evaluation study is probably the best way to find out if a programme creates a certain difference. What we observed during STEP, as Christine in her foreword also described, is that caregivers felt encouraged by the home visits and having someone coming to their house to keep track of the progress of their child, listening to their child’s and their own needs. The need to motivate caregivers, apart from helping the child progress, addressing challenges in taking care of the child and how to deal with stigma, also came up during focus group discussions prior to the first training and start of the pilot.

The following discussion of sub questions goes deeper into each level on which these outcomes were evaluated.

**3.1.2 Sub research questions**

*Sub question 1: To what extend did the skills on activity and participation level of the child increase?*

Most of the children have an increased clinically score for the difficulties mentioned at the start of the project compared to the end of the pilot. Caregivers attributed change to:

1) their own care of the child

2) the fieldworker coming home and showing and supporting them in the home environment to better help their child which helped them to do better themselves

3) the fieldworker arranging assistive devices or coming up with low cost, around-the-house solutions. The importance of providing rehabilitation services at the homes of families to prevent major costs, is supported by Kleinitz (2019).

Factors such as low income, a child having a severe disability, learning that progress will be slow and maybe limited and having worries about family support also influenced to what extent caregivers awarded increase of skills as positive. Hartley et al. (2005) found, in a Ugandan study on coping of caregivers that when having a child with a disability, factors such as income can influence coping behaviour as basic necessities such as clothing and good food are more difficult to get for caregivers. For some children in this evaluation study, even if skills of fieldworkers as well as caregivers would increase, but the child and family couldn’t be provided with basic necessities, scores would remain low.

Grieving for changing expectations about the future and the child’s development seemed to be of influence in talking about increased skills on activity and participation level (Moses, 1987). Especially when the child developed certain skills but was not yet able to do an activity independently - for example bringing only solid food to the mouth but not soft food, -caregivers gave low or even lower scores than at baseline as they had hoped for more progress. Nevertheless, some caregivers did provide higher scores during the endline even though the child could not do a certain activity him of herself but was able to indicate what he or she needed.

These different scores in skills level shows the importance of setting clear and realistic goals and discuss mutual expectations. Even though SMART goals, among other steps of the rehabilitation cycle (Enablement, 2019), were well-discussed during the training, the logbooks studied showed that goals were often set too high, for example goals such as standing while the child couldn’t even sit yet. On the other hand, goals observed were at times not specific enough. The above observations are supported by the fieldworkers who indicated that they want more support with goal setting.

*Sub question 2: To what extend did the knowledge, attitude and skills of the caregiver about their child’s situation change?*

Most caregivers have gained more knowledge about their child’s condition. Combined with seeing progress in functioning of their child gives them courage to hold on. Increased knowledge and observed changes in the functioning of their child also result in more questions about the future, such as the ability of going to school, which was often not addressed yet within home visits by fieldworkers.

Because of the support at home, the caregivers found it easier to cope and continue with functional exercises and advices given. Besides that, most caregivers found ways to better cope with difficulties in the daily life of the child themselves such as helping their child with dressing. For toileting and feeding, more external support was needed to address specific needs and approaches. For about half of the caregivers, the frequency of the home visits went down during the project, which made them less happy about current progress. It does raise the question, what the expectations were from both the caregivers and the fieldworkers from the beginning and if and how these were discussed. For some families, this was their first-time they received support from rehabilitation services. They had given up before and now gained more courage. But as gaining more knowledge about the condition and accepting that development of their child might be slower or limited, this also brought about grief. Many caregivers hope, that getting a better income, could increase the child’s development as materials and services would then be more easily available. Most caregivers did not receive any or limited rehabilitation services, psychosocial support or advices on taking care for their child, many of them just learned what their child’s health condition means and might mean for the future. We learned, especially during the COPM interviews with caregivers, that there may be cultural ‘issue’ to look at as they tend to either score their child’s performance and their own satisfaction about performance as high. Scoring low, for some, might mean that people could think you are a bad parent. In addition, the local therapist felt uncomfortable to ask more indepth questions to prevent the caregiver from feeling sad, while at end line study he learned the need for the specific information to determine to what extent skills increased.

Whereas most caregivers wanted the fieldworker to visit more often, this depended on whether they were also involved in a parent support group that met regularly. Being in a support group also gave opportunities to have parent-to-parent exchange of experiences and advices and also brought about hope. The fieldworkers supported the importance of peer support where caregivers meet either at parent support groups or at rehabilitation centres for example when picking up assistive devices. The importance of such groups is also confirmed by the study of Zuurmond et al. (2018) in Ghana where these groups are seen as social support that help in not feeling alone, experiencing hope and learning to cope. Being able to share their experiences with other caregivers was also mentioned as an implication for rehabilitation services by Nakamanya et al. (2015) from a study in Uganda on infants with neurological impairment.

The frequency of home visits was influenced both by fieldworkers cancelling visits due to not having the time nor finances to do so as well as caregivers postponing visits due to other obligations. There was frustration from the side of the caregivers about cancelled visits whereas the fieldworkers did not want to put the blame on their employer. They would rather have the caregivers not knowing the real reason. Hence the caregivers thought reasons were that they were busy with other families or with personal issues. This underlines the importance of the necessary support to be given by the partner organisatios. The same seemed to apply for the provision of assistive devices. The fieldworkers were depending on other services such as the orthopaedic workshop to do measurements, make a device, do a pre-fitting and deliver timely to the fieldworker. This frustrated some caregivers as it takes a long time to receive the necessary assistive devices.

The fieldworkers contributed change to newly gained knowledge and skills of both fieldworker and caregiver as well as caregivers feeling more encouraged. The caregivers contributed the change also to their ability to take care of the child and their perseverance in taking care of the child and not only to the fieldworkers’ actions. This made most caregivers rate their confidence of taking care of their child high and the fieldworker emphasising and strengthening what competences they already had. Ramanandi et al. (2019) found that evaluating those skills and confidence level of caregivers on coping with their situation was important for applying a family-centred model that enhances the feeling of self-control of caregivers and believing in their own capacity as a caregiver.

*Sub question 3: To what extend did the knowledge, attitude and skills of the fieldworker change?*

The fieldworkers also went through a process of being encouraged in their learning and application of skills. In a study in Uganda with community health workers in maternal health, it was found that low level education and social status influenced their confidence level and coaching was needed to increase their confidence (Okuga et al., 2015). The fieldworkers now feel that they can apply their knowledge also in other children, not just the ones from the pilot. Nevertheless, they indicated that they need to gain more practical skills. Fieldworkers expressed that when they did not know what to do, they wouldn’t go on a home visit. Additionally, some caregivers saw the difference between therapists from the rehabilitation centre and the fieldworkers. This could be positive, feeling more supported, someone looking at how to apply in the home environment. However, it could be explained negatively as well: wanting the fieldworker to be like the therapist whereas the fieldworker should be more of a link between the family and services (see also Okuga et al., 2015).

The fieldworkers had difficulty setting SMART goals (see also Doran, 1981), especially at the beginning of the pilot. At first, goals missed steps in development. During the pilot, the logbook was adapted with a development chart with the milestones of normal development but it is clear that goal setting needs more guidance. Intensive coaching and continued training is needed.

The training increased the confidence of fieldworkers. Coaching after training is essential in helping the field workers to better set goals and develop intervention strategies. There are still training needs, which became clear during working with families and the fieldworkers were also able to indicate specifically which competencies they need to further develop (see also Nakamanya et al., 2015).

**3.1.2 Process**

This research was setup as a pilot study. Because of organizational reasons, the research team was not fully involved in the planning of the study at the start of the project and had this been the case the study design possibly would have been different. Because of the pilot character of the study, it was decided at baseline to use a case study design to evaluate the outcomes of STEP.

It became evident from the logbooks that many appointments with the caregivers and fieldworkers changed. Either they were cancelled or postponed by the fieldworker or caregiver. From the fieldworker’s part, this was at various moments due to not receiving support of their employer, e.g. because of lack of money for transport. As these fieldworkers are not all in full service of the employer, they are dependent on these payments beforehand. For the caregivers who had check-ups with the fieldworker via telephone, home visits could take place on request. Families who lived far from the city received less home visits as travelling to the families took a lot of time for the fieldworker. An important lesson may be that for several reasons, fieldworkers should come from local communities: an issue that is extensively discussed in the CBR literature.

The logbooks were both stated in English and Luganda. Even though in Luganda, some caregivers had trouble reading the logbook and suggested to use clear visuals to better understand specific advices that were given.

During the interviews, an English interview guide, survey and COPM was used. Some of the questions, asked by the local interviewer, required more wording to explain to the caregiver. The translator communicated with the researcher during the interview how questions were translated.

The COPM was carried out before the first training by a local occupational therapist. It missed narrative information of the described difficulties in daily live. Hence, the described difficulties were broadly formulated by the interviewer. Research supports the construct and criterion responsiveness of the COPM [thecopm.ca, 2019]. The COPM manual states that 2 points differences in the rough scores means a clinical change (Law et al., 2014). It worked well to use the 1-10 scoring cards of COPM for the caregivers to rate the performance and satisfaction on specific skills. They did have difficulty providing low scores. We learned that some caregivers were afraid to give low scores as not to be judged as a ‘good’ parent. As stated before the local therapist was afraid to ask in-depth questions, not to make the parent feel sad.

The translation of questions during the interviews was sometimes difficult. Some words have a different meaning in the local language Luganda. Hence, extra information from the respondents was needed to interpret the answers correctly. During the interviews, the translator shared with the researchers when he adjusted the questions, hence the researcher could follow the flow of the conversations.

* 1. **Learnings**

The STEP pilot was designed to find an appropriate family centred approach for providing rehabilitation services within the home of the clients. This approach and the learnings from this study will be written up in a manual that can be used to develop similar services and for intervention research in other cultural contexts within other countries.

**3.3 Conclusion**

The STEP project is a much needed and valuable approach in the work of the Liliane Foundation: providing both families of disabled children and fieldworkers with knowledge, confidence, courage and skills on how to take care of children with CP and making further steps in their development. Overall, identified developmental difficulties improved in all children, with individual differences taking into account. The combination of home visits and meeting other parents for example in parent support groups is of essential importance. Being able to understand a child’s health condition and what to expect for the future, increases confidence among all stakeholders.

**3.4 Recommendations**

This pilot created opportunities to address more developmental and daily problems and challenges of the disabled child and family. This requires a strategy that provides for home visits and extended practical training for fieldworkers. The research team recommends the following:

1. Especially regarding children with severe CP, caregivers and fieldworkers need more knowledge and skills to understand how to support the children. Providing assistive devices for better positioning relieves caregiver burden, reduces feeding difficulties and even increases social participation in the community. Appropriate information is needed on ‘what’s next’ or ‘what’s possible’.
2. Training and coaching needs to include practice for both fieldworkers and caregivers. Demonstrations on daily life activities should be done throughout the training in collaboration with children and caregivers. Demonstrations and practial training can help the fieldworkers, as well as therapists, to formulate and find their gaps in knowledge and skills.
3. Working with training loops and coaching over a period of one year, gives the opportunity in not only implementing knowledge and skills but also in reflecting with fellow fieldworkers on the process of the programme.
4. It needs to become clearer what the scope is of a fieldworker’s role (among other services) throughout the whole life of a person with a disability. Although providing services seems adequate at a certain point in time, different needs will have to be addressed through support of fieldworkers as the child develops through the different life phases
5. To be able to provide this support to families, fieldworkers need support from their organisations in terms of logistic opportunities to go on home visits as well as coaching of the fieldworkers in case of questions and feeling a valued and respected team member.

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**References**

Cantril, H. (1965). *The Pattern of Human Concerns*. New Brunswick: Rutgers University

Press

COPM (2019). *Cross-cultural Applications of the COPM*. Retrieved from

http://www.thecopm.ca/advanced/cross-cultural-applications-of-the-copm/

COPM. (2019). Psychometric Properties of the COPM. Retrieved from

http://www.thecopm.ca/casestudy/psychometric-properties-of-the-copm/

Dan, B., & Paneth, N. (2017). Making sense of cerebral palsy prevalence in low-income

countries. *The Lancet Global Health*, *5*(12). doi: 10.1016/s2214-109x(17)30420-5

Doran, G.T. (1981). There’s a S.M.A.R.T. way to write management’s goals and objectives.

*Management Review, 70*(11), 35-36

Eaton, L. (2019). Taking rehabilitation seriously. *Bulletin World Health Organization*, *97*,

519-520. doi: <http://dx.doi.org/10.2471/BLS.19.020819>

Enablement (2019). Rehapp CP (Version 1.0.3) [Mobile application software]. Retrieved

from <https://play.google.com/store/apps/details?id=nl.enablement.cp&hl=nl> and <https://apps.apple.com/nl/app/rehapp-cp/id1436703718>

Eyssen, I.C.J.M., Steultjens, M.P.M., Oud, T.A.M., Bolt, E.M., Maasdam, A., & Dekker, J.

(2011). Responsiveness of the Canadian occupational performance measure.

*Journal of Rehabilitation Research & Development*, *48*(5), 517–528.

Green, S. E. (2002). Mothering Amanda: Musings On The Experience Of Raising A Child

With Cerebral Palsy. *Journal of Loss and Trauma*, *7*(1), 21–34. doi:10.1080/108114402753344463

Hartley, S., Ojwang, P., Baguwemu, A., Ddamulira, M., & Chavuta, A. (2005). How do carers

of disabled children cope? The Ugandan perspective. *Child: Care, Health and Development*, *31*(2), 167–180. doi: 10.1111/j.1365-2214.2004.00464.x

Holle, F., Ketelaar, M., Morvan, B. & Vermeer, A. (2014). Impact of Livelyhood Support on

the Lives of Children with Disabilities and their Caretakers: A Pilot Study in Uganda. In: Vermeer, A. & Magyarszeky, Z. (eds.). *Disability Care in Africa: Community-Based Rehabilitation in Rural Regions,* 311-341*.* Amsterdam: VU University Press

Kakooza-Mwesige, A., Forssberg, H., Eliasson, A.-C., & Tumwine, J. K. (2015). Cerebral

palsy in children in Kampala, Uganda: clinical subtypes, motor function and co-morbidities. *BMC Research Notes*, *8*(1). doi: 10.1186/s13104-015-1125-9

Law, M., Baptiste, S., Carswell, A., McColl, M.A., Polatajko, H., & Pollock, N. (2014).

*COPM Canadian Occupational Performance Measure* (5th edition). Toronto: CAOT Publications ACE.

Liliane Foundation (2009). An Open World: Promoting Diversity, Empowering Children

Foreword. Retrieved from <https://www.lilianefonds.nl/uploads/media/56054f5a493e3/Beleidsdocument.pdf>.

Liliane Fonds (2019). Empowering children and enabling environment. Retrieved from

https://www.lilianefonds.org/strategy.

Mayne, J. (2001). Addressing attribution through contribution analysis: using performance

measures sensibly, *Canadian Journal of Program Evaluation*, *16*(1), 1-24

Moses, K. (2004). The Impact of Childhood Disability: The Parent's Struggle. Retrieved from

<http://www.pent.ca.gov/beh/dis/parentstruggle_DK.pdf> (Original work published 1977)

Nakamanya, S., Siu, G. E., Lassman, R., Seeley, J., & Tann, C. J. (2014). Maternal

experiences of caring for an infant with neurological impairment after neonatal encephalopathy in Uganda: a qualitative study. *Disability and Rehabilitation*, *37*(16), 1470–1476. doi: 10.3109/09638288.2014.972582

Okuga, M., Kemigisa, M., Namutamba, S., Namazzi, G., & Waiswa, P. (2015). Engaging

community health workers in maternal and newborn care in eastern Uganda. *Global Health Action*, *8*(1), 23968. doi: 10.3402/gha.v8.23968

Ramanandi, V.H., Parmar, T.R., Kalpesh Panchal, J.K., & Prabhakar, M.M. (2019*).* Impact of

Parenting a Child with Cerebral Palsy on the Quality of Life of Parents: A Systematic Review of Literature. *Disability, CBR & Inclusive Development*, *30*(1), 57-93. doi:<https://doi.org/10.5463/dcid.v30i1.793>.

Ratcliffe, R., & Okiror, S. (2019). Millions of Ugandans quit internet services as social media

tax takes effect. Retrieved from <https://www.theguardian.com/global->development/2019/feb/27/millions-of-ugandans-quit-internet-after-introduction-of-social-media-tax-free-speech

Rule, S. (2013). Training CBR Personnel in South Africa to contribute to the Empowerment

of Persons with Disabilities. *Disability, CBR & Inclusive Development*, *24*(2), 6. doi: 10.5463/dcid.v24i2.180

Schneider, M., & Hartley, S. (2006). CBR International Classification of Functioning,

Disability and Health (ICF). In Hartley, S. (Ed.), *CBR as part of community development, a poverty reduction strategy* (pp. 96 - 115). London: University College London, Centre for International Child Health. Retrieved from https://asksource.info/cbr-book/cbraspart\_book.pdf

Smits, D.-W., Gorter, J. W., Riddell, C. A., Voorman, J. M., Rosenbaum, P. L., Palisano, R.

J., Walter, S.D. Hanna, S.E., van Wely, L., & Ketelaar, M. (2019). Mobility and self-care trajectories for individuals with cerebral palsy (aged 1–21 years): a joint longitudinal analysis of cohort data from the Netherlands and Canada. *The Lancet Child & Adolescent Health*, *3*(8), 548–557. doi: 10.1016/s2352-4642(19)30122-1

Thelen, E., & Smith, L. B. (2006). *A dynamic systems approach to the development of*

*cognition and action*. Cambridge, MA: MIT Press.

Vermeer, A., & Magyarszeky, Z. (2014). *Disability care in Africa: community-based*

*rehabilitation in rural regions*. Amsterdam: VU University Press.

World Health Organization (2002). Towards a Common Language for Functioning, Disability

and Health; A guide for beginners learning to use the ICF. Retrieved from <https://www.who.int/classifications/icf/icfbeginnersguide.pdf?ua=1>

Yorke L., & Ogando Portela, M.J. (2018). Psychosocial Scales in the Young Lives Round 4

Survey: Selection, Adaptation and Validation. Retrieved from https://assets.publishing.service.gov.uk/media/5b9a89a240f0b6786cf0f4fa/YL-TN45.pdf

Zuurmond, M., Nyante, G., Baltussen, M., Seeley, J., Abanga, J., Shakespeare, T.,

Collumbien, M., & Bernays, S. (2018). A support programme for caregivers of children with disabilities in Ghana: Understanding the impact on the wellbeing of caregivers. *Child: Care, Health and Development*, *45*(1), 45–53. doi: 10.1111/cch.12618